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ABSTRACT

Discussed in the booklet are approaches for citizens to use in helping the silent minority--mentally retarded (MR) children and adults--attain their rights to life, liberty, and the pursuit of happiness. The MR person is described to be one of 6 million retarded Americans, to benefit from education although his ability to learn is limited, to have special needs such as speech therapy, and to be unable to protect his own interests. Discussed under the MR person's right to life are the right to be born healthy, advocacy programs, the dilemma of guardianship seen in parents' concerns for the future of their MR children, health insurance legislation, habilitation, improved institutionalization, and ways citizens can protect the life of MR persons. Discussed under the right to liberty are the trend toward normalization; considerations on institutionalization such as correct diagnosis, court procedures, prison problems, legislative reform, zoning barriers; and what the citizen can do to assure liberty for the MR population. Discussed under the right to the pursuit of happiness are the right to an appropriate education, the right to a place in the labor force, fundamental personal rights such as marriage, the right to be treated as an individual equal to other citizens, and what the citizen can do to protect the pursuit of happiness of the MR person. Sources of information on legal rights of the mentally retarded and background literature are included. (MC)

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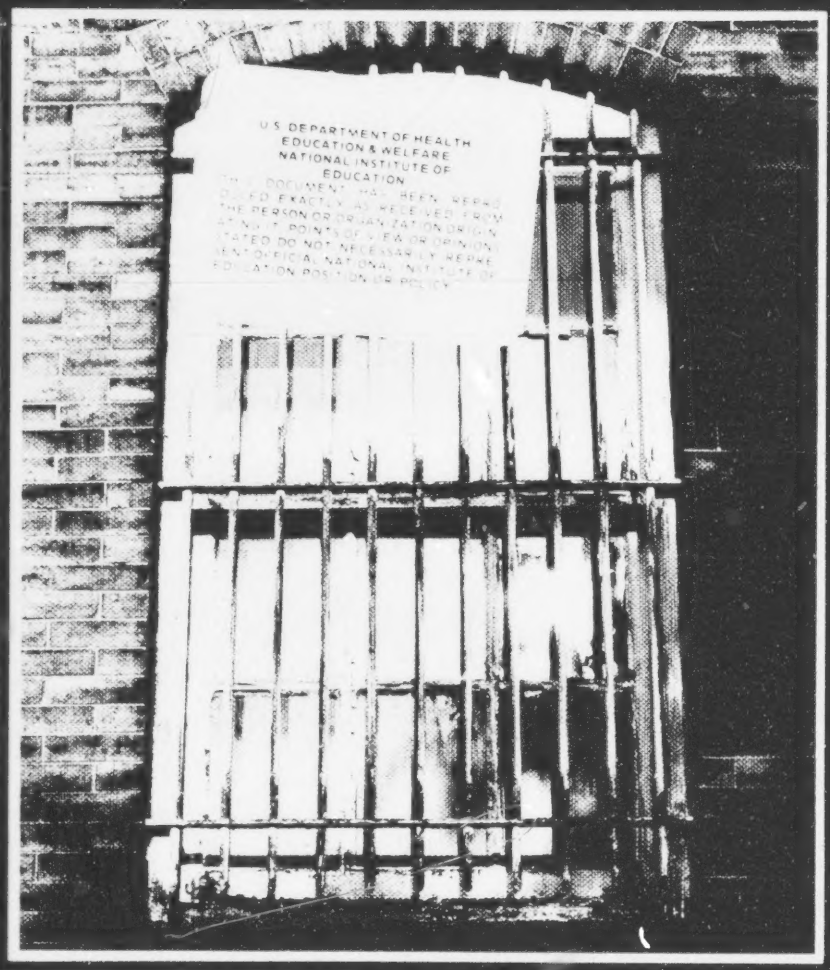
SILENT MINORITY



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PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

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SILENT MINORITY

The President's Committee on Mental Retardation
Washington, D.C. 20201
DHEW Publication No. (OHD) 74 - 21002

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PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

The President's Committee on Mental Retardation was established by Executive Order of the President in 1966.

The Committee is composed of 21 citizen members and two ex-officio members, appointed by the President to advise him on what is being done for the mentally retarded; to recommend Federal action where needed; to promote coordination and cooperation among public and private agencies; to stimulate individual and group action; and to promote public understanding of the mentally retarded.

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SILENT MINORITY

A person who falls within the wide range of disabilities known as mental retardation is frequently denied recognition as a full citizen of the United States of America.

The mentally retarded person's ability or potential may be considerable. Even so, the label of mental retardation may be used to deny marriage, children, employment, voting rights and numerous other opportunities to life, liberty and the pursuit of happiness.

He is one of six million mentally retarded Americans. He has limited learning ability, but he can benefit from education. Our society often says he "doesn't fit" into current school programs, even though in more than five out of six cases he can learn vocational and social skills through appropriate education.

He may have special needs — speech or physical therapy — a wheelchair — eyeglasses. Our national experience and practice has been to deny him the care and training he requires to live a full life, enjoy liberty and pursue happiness.

He is unable to protect his own interests and has little access to the legislative or judicial ear.

Historically, American minorities have organized, developed power through leadership and found dynamic spokesmen. They have demanded their rights.

Many mentally retarded citizens cannot organize themselves. They need others to speak with and for them. There must be litigation and legislation in their interest. We must not wait for them to demand their rights.

For they are, indeed, the silent minority.

SILENT MINORITY deals with life, liberty, and the pursuit of happiness by retarded citizens. Under these three rubrics, it groups a host of legal problem areas facing those citizens, followed in each case by concrete suggestions of "What You Can Do."

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PREFACE

Our founding fathers declared that "all men are endowed by their Creator with certain unalienable rights; that among these are life, liberty, and the pursuit of happiness."

But a silent minority — America's 6 million retarded citizens — are often denied these rights. The denial may begin even before birth, for if the prospective mother cannot obtain adequate nutrition, her child is likely to be born with an underdeveloped brain. In today's complex world this is an almost certain bar to a full life.

And where is liberty for the retarded youth who becomes involved in a minor offense that might draw a six-month sentence for a so-called "normal" person, and is committed to an institution for an unlimited period?

How far can a retarded man or woman pursue happiness if not permitted to marry, as was the case in 40 states at last count?

To focus attention on these and related problems, the President's Committee on Mental Retardation (PCMR) called the first national conference on "The Mentally Retarded Citizen and the Law." Some 250 specialists in both the legal and social science aspects of mental retardation gathered in Columbus, Ohio, May 3-5, 1973.

The intensive sessions produced 21 research papers which articulate the bases for emerging legal doctrines and amplify new ideas for future legal development. These scholarly writings will be published in a volume titled "The Mentally Retarded Citizen and the Law."

In SILENT MINORITY conference discussions are highlighted as a guide to possible action by all men and women of good will. The statements quoted in this publication were delivered during the conference by the faculty, and do not necessarily represent the views of PCMR.

But it is the view of PCMR that the problems discussed here deserve the attention of every American, for as long as *any* citizen is deprived of his rights, the rights of *all* citizens are impaired.

Lawrence A. Kane, Jr.
Conference Chairman and
Chairman, PCMR Legal Rights
Work Group

The quotations in this publication were delivered during "The Mentally Retarded Citizen and the Law" by conference faculty, whose listed positions are those held during May, 1973.

LIFE

When a Down's syndrome (mongoloid) child was born with an incompiete esophagus, the parents withheld their consent to an operation and insisted that no intravenous feeding be given. The baby was left to die. One of the nurses told the story to friends, and pressure was exerted on the hospital authorities. The doctor on the case explained that the operation was expensive, but he offered to perform the surgery free. There were five offers of adoption for the baby. Because of all the newspaper publicity, the hospital began feeding the baby intravenously. But it was too late. The helpless child gave up her struggle and died of starvation—April 29, 1973.

The idea of mercy-killing is not peculiar to the 1970's. A number of years ago, doctors were told, "Patients whose illness, according to the most critical application of human judgment, is incurable, can be granted release by euthanasia." Adolph Hitler issued that decree in 1939. Its use by the Nazis to kill millions of Jews and a smaller number of people with mental retardation, epilepsy and other problems should dramatize forever the danger of giving the State the right to decide who may live.

We often seem to equate the value of a human being with a high intelligence score, physical strength and behavior that presents no problems. Yet, if we believe the moral principles on which this country was founded, we must agree that the retarded citizen has the same right to live as any other American.

THE RIGHT TO BE BORN HEALTHY

Louise first became pregnant when she was 18. She had received no public health services, health edu-

cation or contraceptive advice. Her prenatal care was inadequate. She contracted rubella, and abortion was unavailable to her even if she had wanted it. She had a rubella-damaged child — deaf, blind and malformed. She was soon pregnant again and had a little boy. He ate lead-based paint chips off the windowsills; and Louise then had two severely retarded children. Louise represents a classic failure of the community at all levels. Less than two years later, she had another little girl. Hopefully, we're a little wiser now and will help her protect her third child.

President Richard Nixon set a national goal to reduce the incidence of mental retardation by one-half by the year 2000. That goal is within our grasp if professional and citizen forces apply their existing scientific and social knowledge.

Mental retardation can be caused in over 200 known ways (and in other ways not yet understood). Some of the causes affect the fetus and result in the birth of a mentally retarded child. Currently, it is possible to diagnose certain types of mental retardation before the child is born. Moreover, certain infectious diseases to which the pregnant woman might have been exposed, or certain medications which she might take, greatly increase the probability of her having a mentally retarded child.

The expectant mother, in such cases, should be apprised fully of the situation so that she can decide whether or not to proceed with the pregnancy. A recent Supreme Court ruling has indicated the constitutionality of services to permit termination of pregnancies.

Frequently, environmental factors can cause mental retardation to develop in a child who had been normal at birth. There is general agreement that no matter whether the retardation starts before or after birth, a single factor, poverty, has been shown to have very great impact.

Impoverished conditions can twist a beautiful pregnancy into a mother's nightmare. Inadequate medical care, insufficient food and impoverished surroundings can cause a healthy fetus to be born a mentally retarded child; they can cause a healthy child to evolve into a mentally retarded child.

Malnutrition may impede growth of the fetus' brain, especially near the end of pregnancy. Since various brain and nerve cells form at different times in the fetus, improper nourishment at any period in a pregnancy may cripple the child's future ability to learn. And if a baby is born prematurely, he may lose the opportunity for his last surge of brain growth before birth.

Although many have argued for a legal and human right to be born normal, this concept has not yet become an established legal right. Courts have been reluctant to expand constitutional guarantees in this direction, and legislators have been limited by either lack of understanding or confused priorities.

We must marshal citizen power to defend the human right to be born and remain normal. Currently, poverty and malnutrition are areas where legislative action may speak more effectively than litigation. Many needed reforms in these areas await introduction on state and national levels. Others remain pending in legislative committees. Action to reduce poverty and provide adequate nutrition is essential to a reduction in the incidence of mental retardation.

It is reported that only about 15 states consider unborn children as dependents and thus allow Aid for Dependent Children (ADC) to preg-

nant women. Since Medicaid and ADC are usually linked, the denial of ADC to a pregnant woman with no other children means that she is not likely to receive medical care through Medicaid.

Food stamps present one possibility for obtaining needed prenatal nutrition, but they have not proved an adequate solution. For normal development of the fetal brain, the expectant mother needs 110 grams of protein and 2500 calories per day. A 10-state nutrition survey, however, showed that a low-income, pregnant woman on food stamps had an average daily intake of about 60 grams of protein and 1500 calories.

ADVOCACY

As children, adolescents or adults, mentally retarded individuals should have protected rights to life, liberty and the pursuit of happiness. This protection requires more than abstract services. It requires more than laws. It requires advocates to represent vigorously the personal and property interests of the powerless.

Advocacy can take many forms. The right to legal representation, or legal advocacy, has been established in criminal cases, but the right to counsel in civil cases is an unopened frontier of special importance to the retarded. Personal guardians, acting in a quasi-parental role, are often advocates. Trustees, who administer property and concern themselves with an individual's financial welfare, can be advocates. A new and important concept is that of the "citizen advocate" who volunteers to represent the interests of a mentally retarded client as if those interests were his own. Citizen advocates are both protectors and companions – they may be urging

"Those who have the most gifts have the greatest responsibility."

Eunice Kennedy Shriver
Joseph P. Kennedy, Jr. Foundation

changes upon institution superintendents, helping clients obtain community services, or attending sporting events with them.

An advocate's allegiance must lie with the person he represents, and a major goal in creating advocacy systems is to avoid conflicts of interest. For example, a conflict of interest exists when, as often occurs, a state simultaneously controls institutions or community services and exercises guardianship of the institutional residents or service users.

Citizen advocacy programs exist partially to provide safeguards, checks and balances, for other agency-directed advocacy services. Only now is citizen advocacy being widely implemented, with training programs for leaders.

FAILURE TO ALLOW FAILURE: THE DILEMMA OF GUARDIANSHIP

Have you ever made unwise use of your time? Chosen a friend who consistently took advantage of you? Received the wrong change at the store and not noticed it until later? Making mistakes makes learning. It doesn't always indicate that controls are needed. When a person makes a wise decision, he is proud, and he gains self-esteem. Mentally retarded individuals are no exception.

Our guardianship laws have long been rigid and over-protective. They have transferred total decision-making power from the retarded person to his guardian, thus requiring a choice between total control or no control. Guardianship law reform should stress more flexibility, leaving the retarded citizen free to fail (as others fail) in some areas, restricting him only to the extent absolutely essential to his welfare. Some states are now experimenting with various forms of "limited" guardianship, which recognize the variety of needs found among our retarded citizens.

WHAT HAPPENS TO MY CHILD WHEN I DIE?

A severely retarded 30-year-old woman sat each day listening to records, her only interest. Her father and mother denied themselves luxuries to leave a large trust fund for her care in the community, but after their deaths, the trustee had her institutionalized. The institution took away all her records and record player. Then she merely sat. She was placed in an infirmary because her eye was poked several times by another girl in her cottage.

A friend called the bank and accused it of not fulfilling the spirit of the trust. That friend was subsequently appointed guardian.

The guardian is now trying to purchase a home with a small part of the trust funds, with the goal of creating a group home in the community for the girl and other severely retarded persons.

Since state laws vary, questions regarding lifetime care of a retarded person should be answered by a practicing attorney in the state where the retarded person lives.

Parents of retarded children frequently ask similar questions. Will my child always have a friend/advocate and protector of his legal and human rights? Should we permit him to inherit our money and property?

Parents may not have sufficient assets to pay for lifetime care of their child. They often ask if they can lawfully leave money to him which cannot be spent for his basic costs of care. And they want to know if government will deny the child eligibility for financial assistance or benefits.

In general, naming an individual trustee or guardian with specified

successors answers the advocacy problem. The executive of the local Association for Retarded Citizens may be named as the guardian or trustee with power to appoint another qualified person.

If parents desire a bank or corporate trustee, they may be encouraged to form a co-trusteeship. The individual trustee could have power to spend or not spend trust assets and to substitute another bank or corporate trustee. The bank, in turn, could invest, manage and account for trust assets and income.

Likewise, most lawyers advise against permitting a retarded person who cannot now manage money, property or other affairs to inherit or own property. The individual may not spend his inheritance wisely. In addition, creditors, including government, will either claim most of the assets as reimbursement for costs of care or will deny government financial assistance and benefits until almost all of the assets have been expended.

In many states a discretionary trust provides the best method to assure care. Under this plan, spendthrift provisions protect assets and income from creditors, including government. Trustees also have sole discretion in spending trust monies and income for items that are not basic costs of care or not covered by government benefits. These items might include a TV, radio, record player, vacation, trip to a baseball game, new dress or suit, and inspections and evaluations of social, work and living conditions.

Can the retarded person walk, talk, toilet and dress himself; take a bus around the city; be employed? Trustees and the lawyer must know more than the condition of the retarded person's health. They must know his condition of dependence and understand how it may change.

Trustees should be instructed to periodically check laws relating to government assistance and service; to survey programs of possible benefit to the retarded person; to study work and living conditions of the retarded person; and to seek expert assistance to implement change where needed.

Trustees should also verify that the retarded person's legal rights are not being violated. For example, is the retarded citizen unlawfully denied a public school education, vocational training or the rights to vote and marry?

Too frequently, lawyers may not be prepared to handle these special problems. With few exceptions, law schools do not train or teach students to handle probates, trusts, wills and estate planning as they affect mentally retarded citizens.

HEALTH INSURANCE

Mentally retarded individuals, like everyone else, need health care. Health insurance could be one means of providing a more secure life for a mentally retarded person and his family. There are, however, numerous inadequacies in both private and public coverage for mentally retarded individuals.

Many of our retarded citizens are poor and cannot purchase insurance protection. Because so many employable retarded citizens are unable to find work, coverage by employee group health plans is, at best, spotty. An increasingly large number of retarded adults are being hired in non-profit sheltered workshops. These workshops need to increase their efforts to obtain group insurance coverage for their employees. State laws which restrict retarded citizens from making contracts further limit the availability of insurance protection.

For the more seriously retarded citizen, the most important private health coverage is dependent status under his parent's group insurance policy. Adult retarded family members have often been excluded from such coverage. The Health Insurance Association of America worked with the National Association for Retarded Citizens, to develop a model law (now adopted in over 30 states) which requires that a retarded dependent be continued on a group policy as long as the coverage exists.

When the financial and contractual hurdles are overcome, retarded persons usually can purchase individual health insurance. However, they are often classified as "substandard risks" without conclusive evidence, requiring higher premiums or in some cases resulting in denial of coverage. They should be subject only to the same risk criteria as other citizens.

Insurance is a highly regulated industry. Therefore, legislation and regulatory amendment are the most available means to improve insurance protection.

Public assistance health programs can help fill the gaps left by private health insurance programs. Medicare (includes medical care for the disabled as of 1974), Medicaid, Champus, Veterans Administration plans, and Workmen's Compensation provide some health coverage. Benefits under these programs are helpful, but need enlargement.

National health insurance proposals have suffered lengthy debates and received little action. Although most of the major proposals contain insufficient coverage in the mental retardation area, they would make significant improvements over present situations.

LIFE

WHAT YOU CAN DO
to Protect Life

RELATE OPINIONS TO YOUR LAWMAKERS CONCERNING FOOD PROGRAMS FOR IMPOVERISHED PREGNANT WOMEN.

ENCOURAGE EDUCATION FOR PARENTHOOD IN YOUR LOCAL JUNIOR HIGH AND HIGH SCHOOLS.

WHETHER OR NOT YOU ARE A PARENT OF A RETARDED CHILD, OFFER ORGANIZATIONS LIKE YOUR STATE ASSOCIATION FOR RETARDED CITIZENS YOUR SUPPORT. VOLUNTEER TO BE AN ADVOCATE FOR A RETARDED PERSON.

WRITE YOUR LEGISLATORS TO ENCOURAGE PASSAGE OF LEGISLATION LIKE THAT WHICH INDEFINITELY CONTINUES DISABLED DEPENDENTS UNDER INSURANCE POLICIES. INSURANCE COMPANIES ALSO NEED YOUR ENCOURAGEMENT TO VOLUNTARILY BROADEN THEIR COVERAGE. SEE TO IT THAT ANY NATIONAL HEALTH INSURANCE PROVIDES FAIRLY FOR THE RETARDED CITIZEN.

IF YOU ARE PLANNING CARE FOR A RETARDED PERSON AFTER YOUR DEATH, WRITE TO THE N.Y. STATE ASSOCIATION FOR RETARDED CITIZENS FOR THEIR PUBLICATION, "GUARDIANSHIP OF MENTALLY RETARDED PERSONS," OR TO THE STATE BAR OF WISCONSIN* FOR THEIR PUBLICATION. ENCOURAGE YOUR LOCAL BAR ASSOCIATION TO PROVIDE EDUCATION TO ITS MEMBERS IN THIS FIELD.

UPDATED INFORMATION ON FEDERAL ASSISTANCE PROGRAMS IS AVAILABLE FROM THE NATIONAL ASSOCIATION FOR RETARDED CITIZENS.* REQUEST "ACTION BULLETINS."

USE THE NATIONAL CENTER ON LAW AND THE HANDICAPPED* BY REQUESTING CRITIQUES OF PROPOSED LEGISLATION WHICH MAY AFFECT RIGHTS OF HANDICAPPED CITIZENS.

"Beyond advocacy, we need a principle that the delivery of service is based on needs; that rights are based on needs; and that government has positive obligations to the specific needs of the citizens that need it the most. Rights ought not to equal power and checkbooks."

Professor Fred Cohen
State University of New York at Albany

*Alphabetized addresses, p. 36

RIGHT TO HABILITATION

Becky's pediatrician had little to suggest beyond referral to a neurologist. The neurologist was firm in his advice: institutionalize the child immediately. It was not fair to the other children, to me, or to my husband to invest as much time and energy as Becky needed when she would always remain an infant mentally, he said.

I visited the state institution and was horrified. There were severely handicapped children herded in a large ward with one or two attendants. Row after row of children lay unwatched in cribs. Some were big, some small. Most never played outdoors, and few, I suspected, were ever out of bed. No therapist helped them learn to walk. Obviously there were not enough people to help them do whatever it was they might be able and ready to learn to do.

At age three, my other children had gone to nursery school. I could not find a nursery school for children as severely impaired as Becky. Later, there was no kindergarten, either public or private, that would take a child like Becky.

At six, she was too retarded for the public school classes for the physically handicapped and too unsteady on her feet for the classes for the retarded. Besides, she was not toilet trained. She was clearly ineligible for everything that was offered. Each program had its own restrictions. The public school personnel recommended the state training school as an appropriate placement for her.

The newest, shiniest buildings, programs and techniques become little more than concentration camps if underfunded or operated by people who believe retarded persons are sub-human.

"When I first saw her, she lay nude in a small, dirty, solitary confinement cell. She wouldn't talk to anyone — wouldn't even hold out her hand. Tests couldn't register her low IQ. We got her out of that seclusion cell. We placed her in a program with one staff member for her, three shifts a day.

"In four months I went back to visit her. She was dressing herself. She was feeding herself. She played a record for me and showed me the paintings she had done. She talked to me. Now, she is no longer considered to be severely retarded."

Bruce Ennis, Esquire
New York Civil Liberties Union

Untrained or overworked institutional staff have been known to shut people in locked boxes or isolation rooms when they can't control their behavior, to tie them to chairs, to call them degrading nicknames. These practices and worse are more prevalent in institutions for the retarded than most of us imagine. In the community it may not be much better, for the retarded person often is excluded from programs, or relegated to programs that are understaffed or lack trained leadership. And conditions comparable to those of bad institutions can be found in some community-based facilities as well.

Many retarded persons can become self-sufficient. They can do work as important and honorable as anyone else. Competitive employment is an attainable goal for most. Productive, sheltered employment provides a legitimate goal for others. In all cases, training can increase independence. Training, employment and independence are noble, proper and productive goals for habilitation.

The legal right to habilitation has evolved from recent application of established constitutional concepts. It grew from an analogy to the right to treatment for the mentally ill.

WYATT v. STICKNEY was placed before the Federal court in Alabama in 1970-1971. The plaintiffs alleged that residents in the state's two mental hospitals and one institution for the mentally retarded were receiving inadequate treatment or habilitation and that this violated their constitutional rights.

Since the state had deprived the residents of their liberty on the

basis of their retardation, the attorneys argued that the state must provide habilitation designed to return them to liberty, release them, or establish a legitimate reason for their confinement.

In early 1972, Judge Frank Johnson declared habilitation services to be inadequate and issued detailed orders to improve the institutions, reduce institution populations, and eventually to return many mentally retarded residents to more appropriate community habilitative settings.

The court took constitutional concepts like due process, equal protection under the law, and protection from cruel and unusual punishment and applied them to the mentally retarded citizens at Partlow. It recognized that the mentally retarded have constitutional rights and cannot be placed by the state in great barns to be forgotten. It articulated what it called a right to habilitation. If this right is upheld on appeal, it will be a legal landmark on the road to a better life for the retarded.

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN v. ROCKEFELLER resembles *WYATT v. STICKNEY* by demanding legal protection for mentally retarded citizens. The complaint includes demands that Willowbrook State School residents be afforded equal protection and freedom from cruel and unusual punishment. It sought a court order for a full range of habilitation services: additional staff; adequate medical care for the residents; and a ban on isolating residents.

While Federal District Court Judge Judd found no constitutional right to treatment, he did find that the constitutional principles of due process, equal protection and protection from cruel and unusual punishment were applicable to the residents of Willowbrook. He therefore granted interim relief which calls for substantial effort and expense by the state to improve conditions and programs at Willowbrook.

The final decision in this case is yet to come, but the basic principle is clear: mentally retarded citizens have legal rights, and present practices in most institutions violate those rights.

Cases like *WYATT v. STICKNEY* and *NYSARC v. ROCKEFELLER* have increased public awareness of the inhuman conditions in many state institutions. One result of this litigation is the pursuit of progressive legislative reform in several states to set institutional standards consistent with the constitutional and human rights of mentally retarded citizens. Another result is the accelerated development of community programs as alternatives to institutionalization.

MAKING BAD MISTAKES BETTER

Contemporary professional opinion generally regards isolated, large-scale, full-time residential institutions as undesirable. Some budget and policy-makers are convinced that institutions are so outmoded that we can forget them, while we devote all resources to new community programs. However, institutions have existed for over a hundred years. It is unlikely that legislatures will simply throw away the buildings or that staffs will disappear overnight.

Are we going to condemn another generation of retarded citizens to continue to live in the Partlows and Willowbrooks while we develop community alternatives? It is essential that some resources be used to raise institutional standards.

There are about 200,000 people in state institutions in the United States. Some are excellent facilities. Most are understaffed and under-funded. With proper training, at least a third of the

residents could become fully capable of community-based living.

Institutions must come to be regarded as special purpose units. They can be re-oriented to offer emergency and temporary services; intensive care and treatment for the severely and profoundly retarded and for the multiply handicapped; respite care for families of the retarded; and highly specialized habilitation services for selected retarded persons on a non-residential basis.

Contact must be maintained with individuals who leave institutions to assist their progress and to ascertain what types of community placements are the best alternatives to wholesale institutionalization. That contact must interfere minimally with the individual and his family and concentrate on assuring that when he leaves an institution it is to go to a better place in the community.

Habilitation must be the key concept in future programs for retarded citizens, whether in institutions or communities. It may become so through enlightened administrative action, through legislation, or if necessary, through litigation.

WHAT YOU CAN DO

to Further Protect Life

THE ACCREDITATION COUNCIL FOR FACILITIES FOR THE MENTALLY RETARDED* CONTINUALLY REVISES ITS ACCREDITING STANDARDS FOR COMMUNITY AGENCIES AND INSTITUTIONS. INSIST THAT ORGANIZATIONS IN YOUR AREA APPLY FOR AND MEET THESE STANDARDS.

FIND OUT IF LAW REVISIONS REGARDING INSTITUTIONAL COMMITMENT AND HABILITATION HAVE BEEN PROPOSED OR COMPLETED IN YOUR STATE. SHARE THE INFORMATION YOU FIND WITH FRIENDS. WRITE OFTEN TO YOUR STATE LEGISLATORS.

CLASS ACTION SUITS ARE COSTLY IN TIME AND MONEY, BUT SOMETIMES ARE A NECESSARY LAST RESORT WHEN OTHER ATTEMPTED REMEDIES FAIL. HAVE YOU HEARD OF ANY RECENT CASES CONCERNING HABILITATION OF INSTITUTIONAL RESIDENTS THAT YOU CAN SUPPORT IN ANY WAY?

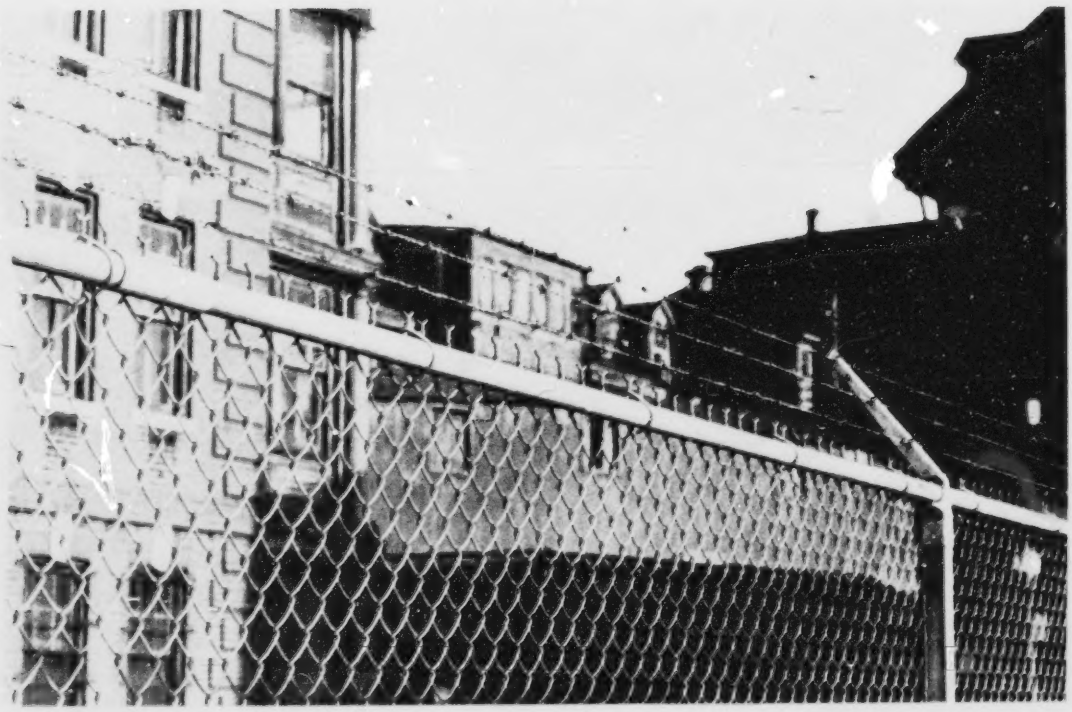
WRITE FOR A LEGISLATIVE CALENDAR FROM THE U.S. SENATE SUBCOMMITTEE ON THE HANDICAPPED.* SO THAT YOU KNOW WHAT FEDERAL PROVISIONS ARE PROPOSED AND CAN RESPOND ACCORDINGLY TO YOUR LEGISLATORS.

"I remember an interesting debate I had with a fellow Senator of mine in California. We were debating special education classes, and he said, 'Oh, you spend all this money on these kids and you work with them two years and all they learn is how to go to the toilet.' He is a good man. He is not evil. He just did not know. I said, 'Senator, if I had to choose to learn one of two skills in my life, and one was reading and one was toilet training, I would take toilet training. That is very, very important learning.'"

The Honorable Clair W. Burgener
U.S. Representative, California

*Alphabetized addresses, p. 36

LIBERTY



NORMALIZATION

Two years ago, Phil couldn't walk or talk. The institution had labeled him autistic. After 12 years he left the institution and has since progressed through community developmental centers and a training and education program to an almost independent life.

John was in an institution for 37 years. After discharge, it took only three months of training before he was ready for employment.

These cases are not special. They are typical of the success of community programs.

For decades, many persons have been denied the right to liberty by being committed to institutions without due process; being left to sit their days out on benches or to do menial work without pay; never to be considered for release.

A few years ago, one state embarked on a program to rid itself totally of large-scale, resident institutional care for the mentally retarded. It set out to prove that restriction is not the only way to deal with mentally retarded citizens.

In 1968 there were 2,400 people in the state institution for the mentally retarded. In 1973 there were only about 1,000. Costs per person, per day, significantly decrease as individuals advance through 14 community services that help achieve normalization. Normalization of the mentally retarded makes sense in human values. It also makes sense in dollars.

Normalization is the name of such programs, now under way in several states. Normalization stresses the values of helping mentally retarded individuals to live as much like the rest of society as possible and of allowing them to enjoy the right to liberty.

People who could not walk have learned to walk. People who were a drain on the public treasury have become tax-paying citizens. Judges, legislators and laymen have seen an adult confined to a crib and a few months later have seen him working in a sheltered workshop in the community.

THE LEAST RESTRICTIVE ALTERNATIVE

Most Americans believe that people should be free to live as they please and that government should intrude on their lives only when absolutely necessary. Our Constitution is based on this principle, and the Constitution applies equally to all citizens, including those who are labeled mentally retarded. When government must interfere with liberty, the intervention should be the least restrictive possible.

The term "least restrictive" is not found in the Constitution. But Supreme Court decisions reaching over many years have insisted that when a state pursues a legitimate goal that involves restricting fundamental liberty, it must do so by using the least restrictive alternative available. As in *WYATT v. STICKNEY*, this principle increasingly is being applied to the rights of mentally retarded citizens. Under it, as a prerequisite to institutionalization of a mentally retarded individual, a state can be required to prove first that the individual cannot be habilitated in the community.

SHORT ROAD TO THE INSTITUTION

David's parents requested that the court institutionalize him. David, 19, was a school drop-out who had difficulty finding and keeping jobs and handling money. His parents felt he was an unmanageable burden. The court was convinced he was mentally retarded and that he could not do pro-

ductive work. David was committed to a state institution for the mentally retarded. After eight months of working on an institutional groundskeeping crew, David became foreman of eight other similarly committed crewmen. Institutions contain thousands of Davids who are found "unfit" for community work but provide the very fiber of institutional maintenance and support systems.

As we awake to the inadequacies of institutional placement and develop a flexible range of community services, the commitment process must be revised.

Almost 90% of commitments are termed "voluntary." The retarded person is usually presented at the initiative of his parents. The parents are allowed to consent to commitment, which sometimes involves a court ritual where no opposition or alternatives to institutionalization are presented. Since most institutions offer only poor custodial care and are prison-like in appearance and restrictiveness, "voluntary" commitments are frequently involuntary or at least non-voluntary for the retarded persons involved. The interests of parent and child may conflict, but these conflicts are often ignored by the courts. Present commitment statutes frequently deprive retarded citizens of liberty through antiquated procedures that do not recognize the potential of living and growing in a normal environment.

PAVING A NEW ROAD

An accurate diagnosis of mental retardation is a necessary prerequisite but not a sufficient justification for commitment. Placing a person in an institution is a value determination about what we want for people, and

"No one would require a full due process commitment hearing before a parent placed a retarded child in a week-end respite center. But all of us would require a full due process commitment hearing before a parent placed a retarded child in a state prison. The question, then, is whether our state institutions for the retarded are closer to prisons or weekend respite centers."

Bruce Ennis, Esquire
New York Civil Liberties Union

what, as a society, we are willing to give them.

Courts can be particularly helpful in the commitment process because they have power not only to explore alternatives but to order implementation of alternatives. For this reason, hearings should be mandatory for all commitments unless waived by the retarded person and his counsel. Judges should be required to consider less restrictive alternatives, then detail the reasons for commitment and specify an habilitation plan if the person is to be committed.

Some form of periodic review should be available to assure that the person is being habilitated for release as soon as possible. The review need not be a judicial one, but the courthouse route should be open for use if the need arises.

Perhaps the institution is the only place where a particular kind of physical therapy or vocational training is available for a retarded citizen. If the court specifies a particular reason for commitment, then the individual should be returned to the community after the institution's function is completed. He definitely should not be held in the institution to provide it with unpaid or underpaid labor.

INSTITUTIONAL PEONAGE

The state commissioner asked all institution superintendents to send him lists of mildly retarded young people with a high prognosis for successful return to the community. Later, he announced a new training center for retarded adolescents to be returned to the community. However, the superintendents claimed that those on the lists were not available for transfer to the center, and the center began receiving individuals who did not meet the original criteria. It was found that the institutions were using those most able to return to the community as workers to maintain the facilities, and superintendents were afraid of losing their best laborers.

Those residents who are the least seriously impaired are often the easiest to habilitate and return to the community. Unfortunately for them, they are also usually the most dependable and productive workers in institutions. This conflict accentuates the exploitation potential of unpaid institutional labor, or peonage, surely a deprivation of the right to liberty.

The economic injustice of institutional peonage follows residents into the community if they are fortunate enough to obtain release. Because individuals have not been paid for institutional work, they are not eligible for Unemployment Compensation or Social Security.

Despite changing philosophies about habilitation and the use of restrictive settings, institutional peonage continues. Fewer than ten states now provide significant compensation for work by institution residents, but the abolition of institutional peonage is gaining ground. New York and Indiana have taken the lead with explicit statutory provisions abolishing peonage. The attorney general of the state of Washington recently issued an opinion that institutional peonage constituted involuntary servitude and was, therefore, a violation of the 13th Amendment. A federal district court, in *SAUDER v. BRENNAN*, ordered the Department of Labor to enforce minimum wage benefits of the Fair Labor Standards Act for working residents in institutions. In *WYATT v. STICKNEY*, the court also ordered payment to working residents who volunteer for institution-maintaining labor.

Mrs. Dale, the plaintiff in *DALE v. NEW YORK*, had been released from a mental institution after 16 years of uncompensated institutional labor.

She sued the state for back wages and interest. The state contended that her work in the institution was therapy. But Mrs. Dale testified that when she didn't work, her privileges were rescinded. She also believed that she would be released sooner if she acted "cooperatively." Experts testified that generally work is therapeutic and not exploitative only if fair compensation is paid and the work is an integrated part of a broader, supervised treatment program. The questions raised by *DALE v. NEW YORK* are still being decided, but it is becoming more evident that institutions will not be able to continue forcing involuntary servitude on their residents.

New Jersey has demonstrated what can be done. In the 1950's, the state began a program of hiring institution residents as aides. They were paid $100 a month, given room and board, privileges in the employee dining room, and weekends in the community. The work program was accompanied by adult training and social education courses. The workers' progress and needs were continually evaluated. New Jersey's program has led to the eventual release of thousands of employable residents. Each released resident represented a personal success story, a savings of future tax dollars, and a vindication of the right to liberty.

WHAT YOU CAN DO

to Protect Liberty

HOW DOES YOUR STATE VIEW COMPENSATION FOR INSTITUTIONAL RESIDENT LABOR? WRITE YOUR LEGISLATORS, OR THE APPROPRIATE STATE OFFICIAL IN CHARGE OF INSTITUTIONS.

LABOR UNIONS ACTIVE IN STATE INSTITUTIONS MAY PLAY A MAJOR ROLE IN DETERMINING WHETHER RESIDENT LABORERS WILL BE COMPENSATED. COMPROMISE PROGRAMS MAY BE REQUIRED. WORK TOWARD EDUCATION OF TAXPAYERS, LABOR UNION ORGANIZERS AND LEGISLATORS.

WRITE TO YOUR LEGISLATORS ABOUT HUMANIZED PROCEDURES TO REDUCE UNNEEDED COMMITMENTS AND RESPECT THE RIGHTS OF EACH CITIZEN SUBJECTED TO SUCH PROCEEDING, INCLUDING HIS RIGHT TO PERIODIC REVIEW.

CONTINUALLY STRIVE TO UPGRADE STANDARDS IN YOUR STATE INSTITUTIONS THROUGH YOUR BALLOT AND YOUR LEGISLATORS.

"Because of inadequate funding, institutions are grossly understaffed. To compensate, many attendants resort to practices which jeopardize residents. So, when the institutional staff find it too burdensome to pick up toilet paper strewn around the facility, they lock up the toilet paper. And when residents become dirty, they may be stripped, placed in 'car-wash' lines, and walked between streams of high-pressure water. Often residents are kept in straightjackets or unduly drugged for long periods of time. Or they may be required to perform work for which they receive no pay.

"Generally, residents are not to be released until their conditions have sufficiently improved to warrant release. Under circumstances where no habilitation is occurring, it is often a life sentence. Even citizens who are charged with the most heinous of crimes are given trial by jury and common due process protection, but rarely are the mentally retarded accorded those formalities."

Louis M. Thrasher, Esquire
U.S. Department of Justice
Civil Rights Division

BEFORE THE COURT

A janitor confessed to the murder of a girl and her roommate and recounted facts to the police which only the murderer could have known. It was found, however, that the police subconsciously or consciously infused those facts into the purported confession. The young man was innocent.

The young man's attorney discovered the level of his client's retardation. As it was noted later, his client would have confessed to the murder of Julius Ceasar if the police had asked him. He was overjoyed at having his words listened to with great interest by a group of adults and men in uniform.

A retarded citizen may come before the court in connection with commitment to an institution, or as can happen to anyone in the community, if charged with an offense. Here his retardation may result in his being unjustly deprived of the right to liberty.

Public defenders rarely have social workers and psychologists to assist them in pre-trial preparation, though that aid could prove valuable for clients with mental impairment. Even if the court is aware that a convicted defendant is mentally retarded, it may not be able to provide the necessary help. Since there are few specialized community programs for the retarded offender, the court may have no sentencing alternative other than imprisonment, indefinite commitment to an institution, or complete freedom in the community.

The mentally retarded suspect is in a uniquely damned position before our courts. If his disability remains undetected, his chance of receiving proper court handling is reduced. But if his impairment is recognized, he may receive a long-term institutional commitment without a trial for the alleged offense.

The lack of adequate community programs creates a special hardship for some mentally retarded suspects whose disability comes to the attention of the court. The court may find the suspect incompetent to stand trial and commit him to an institution "until he becomes competent." This type of commitment can become a life sentence without a trial when the institution has no capability to improve the suspect's competency. Such a life

sentence was recently held by the U.S. Supreme Court in *JACKSON v. INDIANA* to be an unconstitutional denial of the right to due process for mentally retarded citizens.

BEHIND PRISON BARS

Prison management commonly complains that mentally retarded individuals require constant and individual staff attention and retarded inmates are likely to be exploited by their more intelligent peers.

Some institutions report that mentally retarded offenders might have difficulty comprehending prison rules and regulations, but they feel it isn't possible to apply separate rules to retarded inmates. Rule violations among mentally retarded prisoners are substantially higher than among other offenders. Since prison behavior affects releases and paroles, the retarded prisoner is more likely to be incarcerated for a longer period of time than a non-retarded person convicted under similar circumstances.

Where prisoner rehabilitation programs exist, they often are not appropriate for or available to the mentally retarded offender.

Many prisons maintain psychiatric wards which serve as segregation units to which both mentally retarded and mentally ill offenders are assigned indiscriminately even though the problems of the two groups are quite different. Parole boards have traditionally denied or delayed parole to persons from these wards.

When the correctional process begins more fully to approach its ideal, the mentally retarded inmate will be a primary beneficiary of the reforms.

IN THE LEGISLATURES

We are well on our way to a unique period of law reform. Many states have re-written their criminal laws; Federal criminal statutes are also being revised.

For the most part, however, the reform measures do not highlight the existence of mentally retarded offenders or their specialized needs. Law enforcement officers and personnel in correctional systems generally are not alerted that the accused or sentenced persons may be retarded and require special care, although police training materials on the subject are becoming more widely available.

The extensive examination of our criminal system now taking place can benefit the mentally retarded suspect and offender if legislators give consideration to those who have special problems and create flexible and effective laws and guidelines.

"Rehabilitation in prison is nonsense. It's a fraud. It's a sham. We don't know how to do it. If we did know how to do it, we wouldn't do it because we don't want to spend the money."

Professor Herman Schwartz
State University of New York
at Buffalo
School of Law

WHAT YOU CAN DO
to Further Protect Liberty

IF YOU BELONG TO A SOCIAL ACTION ORGANIZATION, INFLUENCE YOUR GROUP TO STUDY PRISON REFORM AS IT RELATES TO MENTALLY RETARDED CITIZENS. STUDY YOUR LOCAL AND STATE PRISON BUDGETS. DO THEY REFLECT ADEQUATE FUNDS FOR PERSONNEL AND EFFECTIVE REHABILITATION PROGRAMS? INFORM YOUR LEGISLATORS OF YOUR OPINIONS.

ASK YOUR STATE LEGISLATOR HOW THE RETARDED OFFENDER WOULD BE HANDLED UNDER YOUR CRIMINAL CODE. CAN HE PLEAD INCOMPETENCY? INSANITY? IS HE LIKELY TO BE COMMITTED TO A SEPARATE STATE FACILITY OR RECEIVE LONGER SENTENCES BECAUSE OF HIS IMPAIRMENT? IF YOUR STATE'S CRIMINAL LAWS ARE BEING REVISED, BECOME AN ACTIVE SPOKESMAN TO YOUR LAWMAKERS FOR THE RIGHTS OF THE MENTALLY RETARDED.

"Every study that has been made of the prison system has indicated that, while prisons may be debilitating, dehumanizing and exacerbating for most offenders, they are infinitely more so for the retarded, who cannot profit even by the meager programs in education that the prisons have for normal residents. A retarded person is likely to be exploited and more bitterly dehumanized than his intellectually normal brethren."

Professor Richard C. Allen
Institute of Law, Psychiatry
and Criminality
George Washington University
National Law Center

"If we continue separating people by national background, colors and handicaps, we are all going to become less able to accept the differences that exist among individuals."

Sterling Ross, Esquire
California Association for Retarded Children

BARRIERS TO LIBERTY

Many communities have begun normalization programs only to be stifled or slowed by restrictive zoning ordinances. When an organization tries to open small group homes for community living, it is often met with the zoning restriction, "These buildings shall be occupied only by a single family."

Zoning ordinances sometimes define "single family" as those related by blood, marriage or adoption. In communities where zoning ordinances are less explicit, courts have held that non-related persons can live together if they are a single housekeeping unit. The exclusion from residential neighborhoods of mentally retarded citizens living in small group homes raises serious constitutional issues.

Zoning barriers are often legal hurdles that conceal the true problem —public fear and prejudice. Community fears can push group homes out of residential neighborhoods into crowded commercial or industrial areas, often not ideal settings for effective normalization.

Effective normalization will not occur when neighbors are hostile. Unless neighbors understand and participate in the unit's functions, the home will not be truly integrated into the community.

Safeguards can be provided for neighbors. State licensing procedures can assure that group homes will be properly maintained. Care must be taken to avoid concentrating too many group homes in the same neighborhood. But the right to live in the community is a fundamental aspect of the right to liberty.

Local zoning ordinances restricting that right are as repugnant to the concept of a free society as the civil or criminal procedures that shut retarded citizens in institutions without just cause and without due process.

WHAT YOU CAN DO

to Further Protect Liberty

CALIFORNIA PASSED LEGISLATION DECLARING THAT, FOR ZONING PURPOSES, GROUP HOMES FOR THE HANDICAPPED ARE A SINGLE FAMILY RESIDENTIAL USE OF PROPERTY. COULD NORMALIZATION EFFORTS IN YOUR STATE BE ENHANCED WITH STATEWIDE LEGISLATION OR LOCAL ORDINANCE MODIFICATION? WRITE YOUR LOCAL OR STATE REPRESENTATIVE IN SUPPORT OF SUCH LAWS.

SUPPORT ANY PROPOSED GROUP HOME IN YOUR AREA. NEIGHBORS MAY WAIT FOR YOU TO SPEAK FIRST.

DOES YOUR STATE REQUIRE LICENSING OF GROUP HOMES? ARE THE REGULATIONS COMPREHENSIVE ENOUGH TO ASSIST GROUP HOME RESIDENTS AND REASSURE NEIGHBORS? WORK TOWARD NEEDED REVISIONS.

"If you don't convince the neighborhood of the value of a group home, and the city planning commission won't grant you a zoning permit, then you have to go to court, but that's the last resort. Avoid litigation if you can. It's cumbersome, costly, and creates hostile atmosphere. But if you must use it, it's very important to have your soldiers lined up when you start."

Jo Ann Chandler, Esquire
Public Advocates, Inc.

THE PURSUIT OF HAPPINESS

RIGHT TO AN EDUCATION

Gregory, a mildly retarded boy, was kept home from school by his mother for about two months because he was emotionally upset over his father's recent death. Because of his absence, he was suspended from the third grade without warning or a hearing. His mother had to work, so she asked the welfare department if it could find a school for him. The welfare department accepted him as a ward and sent him to an institution for dependent and neglected children with special education classes. During his third day at the institution he was sexually assaulted. He ran away. When Gregory was found, he was placed in a medium security institution for incorrigible children where no education programs were available.

Gregory is not an isolated example of a retarded person who is deprived of the right to pursue hap-

piness because of inappropriate handling by one of our service systems. If education is seen as a first step toward making that right meaningful, then hundreds of thousands of handicapped children get little or no chance to pursue happiness successfully. And when they become adults, they often are frustrated in the pursuit of happiness by denial of the rights to work, marry, have children, contract and vote.

Forty-eight of our states deem education so important that they make school attendance compulsory. Children or their parents face criminal action if they don't comply. These laws reflect a judgment that education is essential to life in modern American society.

Nevertheless, in almost as many states, a child can be denied education through exclusionary policies and practices that allow officials to decide that handicapped children are too difficult to manage in the school system. Nationally, about one million children are denied access to public education because of their handicaps. The exclusion of children from public schools in the community forces many parents to institutionalize their children. Institutions often lack education programs of any kind. Even where programs exist, institutional education faces the hurdle of educating for community living in an isolated, restricted setting outside the community.

This vicious circle leading to large, permanent institutional populations can be interrupted. Recent litigation has required school systems to adopt policies of zero rejection of children with special learning needs.

In 1971, a federal district court in *PENNSYLVANIA ASSOCIATION FOR RETARDED CHILDREN v. COMMONWEALTH OF PENNSYLVANIA*, entered a consent decree that Pennsylvania's public schools would cease excluding children because of their mental retardation. Furthermore, if a school wishes to move a child from a regular to a special class or school or vice versa, it must notify the parents prior to the change. Opportunities must be provided for an independent reassessment and a formal hearing on the proposed shift.

In *MILLS v. D.C. BOARD OF EDUCATION*, a federal court held that the Constitution requires individually appropriate public education for every child. No longer can mentally retarded children be rejected — thrown away — by the schools. Placing a child on a school waiting list is no longer acceptable. Every child has a right to a share of the educational pie.

APPROPRIATE EDUCATION

Even schools that do not give retarded children a one-way ticket out of public education often place them in a special classroom where all the children are branded retarded.

Placement devices, and even the concept of separate placement, are increasingly under challenge. The primary device used for screening and placing children in special classes is the so-called standardized individual intelligence test. Respected school officials and psychologists admit that the IQ tests are inappropriate to measure the intellectual capacity of many minority children.

A child diagnosed by these tests as having limited capacity frequently is treated as retarded for the rest of his often abbreviated education. Part of the tragedy of such labeling is that teachers who believe a child to be of limited educability tend to lower their expectations of the child accordingly. Then the student usually acts out the label by performing at or below the expected level, even if he is able to do better.

The label of retardation can have serious, debilitating and life-long

HAPPINESS

"Our schools exist to reform society, not perpetuate it."

Dr. Hugh Scott, Superintendent
Washington D.C. Public Schools

effects on the labeled person. A labeled person becomes subject to special discrimination. He becomes a person (or non-person) who is not heard, or if heard not listened to, or if listened to, not heeded. He often internalizes society's judgment in shame, guilt, timidity and unusual acquiescence to authority.

Labels may be inevitable in some cases; they provide a way of ordering things. But because labels narrow options for the person involved, we must minimize the special labeling and discriminatory treatment against mentally retarded citizens.

Due process is the legal theory that can be used to assure fairness when a child is placed in a special class. Due process hearings of the type required by the court in the *PARC* case attempt to assure that educational placement is suitable and appropriate. Hearings create a pressure against segregated classes, and they involve parents in the decision-making process. They require the school to justify changes in a child's educational status.

Damages for false labeling have been requested against school systems in some law suits. These cases are helping to provide the stimulus needed to spur the creation of more culturally relevant and effective testing devices and to minimize the overuse and misuse of all testing devices.

Mental retardation may result from a lack of stimulation during the critical preschool years. An absence of attention and opportunities to share and experience new situations can cripple a child's chance to remain unlabeled. Federal programs like Head Start and its companion outreach

effort, Home Start, attempt to rectify these problems.

If communities counteract physical, social and emotional setbacks during preschool years, fewer children will later receive special labels and suffer from the discrimination that accompanies them. Equal opportunity for public education must continue from preschool through vocational training for young adults. For the retarded person, it is not only a right but a necessity in order to become a happy and productive member of society.

HAPPINESS

WHAT YOU CAN DO
to Protect The Pursuit of Happiness

URGE YOUR LOCAL SCHOOL BOARD TO ADOPT A ZERO REJECT POLICY. LOOK INTO THE BASES ON WHICH CHILDREN ARE PLACED IN SPECIAL CLASSES AND WORK FOR THEIR INTEGRATION INTO REGULAR PROGRAMS WHERE APPROPRIATE.

ASK YOUR SCHOOL-AGED CHILD ABOUT SPECIAL CLASSES IN HIS SCHOOL AND HOW HE VIEWS THE CHILDREN IN THOSE CLASSES. TALK TO TEACHERS AND THE PRINCIPAL TO SEE IF PART OF THE STIGMA OF SPECIAL CLASSES CAN BE ELIMINATED. SUGGEST TEACHER WORKSHOPS ON THE SUBJECT.

DOES YOUR SCHOOL DISTRICT PROVIDE DUE PROCESS HEARINGS FOR SUSPENSIONS AND CHANGES IN EDUCATIONAL STATUS? DISCUSS THIS RIGHT WITH PRINCIPALS AND YOUR SCHOOL BOARD.

ENCOURAGE PARENTS TO CHALLENGE SCHOOL PLACEMENT DECISIONS THAT SEEM INCONSISTENT WITH A CHILD'S ABILITIES.

BECOME AN ADVOCATE FOR EFFECTIVE PRESCHOOL COMMUNITY SERVICES.

SUPPORT STATE LEGISLATION WHERE NEEDED TO PROVIDE MEANINGFUL EDUCATION FOR THE RETARDED.

"Mechanisms for accountability, for insuring each child an educational placement commensurate with developing his full potential, ought to be adopted voluntarily by school districts. Schools should not wait for law suits to be filed."

Stanley Herr, Esquire
National Legal Aid and
Defender Association

IN THE LABOR FORCE

Barbara is 18 and mildly retarded. She is a waitress at a small lunch counter, earns steady wages and shares an apartment with another young woman. Her employer says she was very quiet and nervous when she began work there. Now she is cheerful, confident, and customers like and appreciate her.

Mr. Egbert, her employer, says he hires mentally retarded employees because he believes they should have opportunities to make successes of themselves and completely enjoy life. "After all, if someone hadn't given me a chance at the right time, who knows where I'd be now?"

A report on graduates of educable mentally retarded work-study programs in Ohio shows that 83 percent of the 1,898 graduates of 1972 are employed. All students earned about $5.2 million during 1972-73, paid about $317,000 in Federal income taxes and $80,000 in state taxes. Programs in other states can boast similar successes.

Sheltered workshops and other vocational programs are increasing nationwide. Some mentally retarded individuals work in these programs permanently, while others are prepared

"School officials should know by now that the intelligence tests they use to make classifications are not relevant to minority children. They are making a conscious decision to use these tests with full knowledge of the consequences, so they should be held liable for natural and probable consequences of their decisions to utilize the tests."

Professor Michael Sorgen
University of California
Hastings College of Law

HAPPINESS

"It is essential to our constitutional scheme that stereotyping of men by governments be prohibited, and that stereotyping of men by men not be encouraged and, perhaps, be actively discouraged by government."

Professor Thomas Gilhool
University of Southern California
Law Center

for work in private industry.

Wages paid to handicapped adults in vocational programs are not required to meet the minimum wage standards set by Congress. Instead, they are based on a comparison of the quantity and quality of products produced in private industry. In most of the nation's approximately 900 work activity centers and sheltered workshops, mentally retarded employees work in antiquated facilities with obsolete equipment. The quality of the products from these facilities may be excellent, but the quantity of production often suffers from the lack of modern facilities and equipment. Exemption from the minimum wage law, combined with antiquated facilities and equipment, often results in substandard wages.

Vocational programs train employees to solder, assemble and package by hand. The graduates must later work in mechanized private industry. There, the graduate who thought he had learned a skill must re-learn that skill on modern equipment. Under the Small Business and Investment Law of 1972, qualified rehabilitative facilities will be able to obtain low-interest loans to improve their facilities.

Employers have begun to realize the benefits of hiring mentally retarded persons. In general, a mentally retarded individual usually proves his reliability and desire for doing his job well. In addition, he has less of a propensity toward boredom than others when he is hired for repetitious labor. However, more employers must open their doors to mentally retarded citizens if increased normalization efforts are to succeed.

FUNDAMENTAL PERSONAL RIGHTS

Two mentally retarded individuals from a state institution decided to be married. When they applied for their license, they were asked if they had been in a mental institution or similar facility within the past five years. They said no. After they were married, the school administrator discovered what they had done and tried to annul the marriage. The fact that the couple was already married shifted the burden to the administrator to prove that they were incompetent to enter into a marriage contract. The administrator failed, and the marriage succeeded.

A second couple answered the same licensing question honestly. The clerk refused the license application, but a lawyer was able to reverse the decision because the clerk could not justify why he had made the refusal or why the question even appeared on the application.

Most of our laws are built on the premise that people understand and expect the consequences of their actions. It is assumed that people can easily and clearly communicate their intentions to others, and understand what others communicate to them.

When the law singles out special groups of people as not fitting into the profile of the average man, it often disqualifies them from the benefits of ordinary life. Traditionally, many of the mentally retarded have been declared "incompetent." As a result, it is assumed they can't marry, contract or vote. Children are taken away, and individuals are sterilized.

Marriage, family life, contracting and voting are a fundamental part of normal life. They have also been recognized as fundamental constitutional rights. The Supreme Court has held that a state must have a "compelling justification" before it can deny

"Children should be taken away from a mentally retarded couple only on the same basis that they are taken away from anyone else—on provable neglect."

Patricia Wald, Esquire
Mental Health Law Project

any citizen fundamental rights that other citizens have. For most mentally retarded citizens, there is no compelling justification to deny them these basic rights.

Yet it is done on all sides. Where is the right to privacy for the retarded person in an institution, where toilets are not enclosed, where he has no place to keep his possessions, where his mail is censored?

About 40 states deny a retarded person the right to marry, supposedly because mentally retarded individuals are not competent marriage partners. One out of four American marriages ends in divorce. Many others generate major problems such as child abuse and wife-beating. How many "normal" people could pass a competency test as a good partner or parent?

Involuntary sterilization infringes upon what the Supreme Court, in *SKINNER v. OKLAHOMA*, called "the fundamental right of man to procreate and have children." Often, parents or guardians have a mentally retarded person sterilized without judicial inquiry, regardless of the age of the individual and sometimes without his knowledge. The mentally retarded person may not understand the parental decision and is unlikely to know how to contest it.

A common argument for sterilization of mentally retarded individuals is that the retardation will be inherited by their children. Present knowledge indicates that most mental retardation is not genetically caused and, therefore, cannot be inherited by following generations. Furthermore, many individuals who are mentally retarded for genetic reasons are naturally incapable of reproducing. Persons with genetically caused disorders, whether in the form of poor eyesight, diabetes or mental retardation, should have the benefit of genetic counseling. None of these persons, however, should be subjected to involuntary sterilization merely because of a genetic defect. Conversely, retarded people who genuinely want sterilization should not be denied the right.

Less drastic alternatives like sex education and birth control are apparent but usually not made available. It has been shown that mentally retarded persons are likely to make sensible decisions about birth control and other medical matters if the information is conveyed to them properly and objectively. And they are more likely to react sensibly with persons of the opposite sex if they have experienced normal socialization.

WHAT YOU CAN DO

to Further Protect The Pursuit of Happiness

ARE THERE DISQUALIFYING CLAUSES IN YOUR STATE REGARDING VOTING, DRIVING, MARRIAGE, AND HAVING CHILDREN? DOES YOUR STATE ALLOW LIMITED GUARDIANSHIP? DISCUSS YOUR CONCERNS WITH LEGISLATORS. TALK TO YOUR LOCAL ASSOCIATION FOR RETARDED CITIZENS* ABOUT FORMALIZED EFFORTS TO CHANGE THESE LAWS.

VOLUNTEER TO AID IN COMMUNITY AND INSTITUTIONAL RECREATION PROGRAMS WHICH GIVE MENTALLY RETARDED PERSONS AN OPPORTUNITY TO SOCIALIZE WITH THEIR PEERS OF BOTH SEXES.

ENCOURAGE THE EDUCATION SYSTEM IN YOUR COMMUNITY TO PROVIDE SEX EDUCATION TO ALL STUDENTS, INCLUDING MENTALLY RETARDED YOUNG ADULTS.

IF YOU ARE AN EMPLOYER, CONSIDER MENTALLY RETARDED INDIVIDUALS FOR SOME OF YOUR POSITIONS. CALL YOUR LOCAL VOCATIONAL REHABILITATION OFFICE FOR TRAINED PERSONS TO EMPLOY.

SUPPORT SHELTERED WORKSHOPS AND OTHER VOCATIONAL PROGRAMS THROUGH YOUR LOCAL AND STATE LAWMAKERS.

"Professionals increasingly will be required to improve education and habilitation techniques. Increasingly, they will be asked to clarify reality, debunk myths and provide expertise to the judiciary. Therefore, there is an urgent need to improve the dialogue between mental retardation and legal professionals and engage in exercises of mutual education."

Dr. Philip Roos
National Association for Retarded Citizens

*Alphabetized addresses, p. 36

HAPPINESS

THE RIGHT TO BE YOU

Recent court decisions require that mentally retarded individuals should be treated as equal to other citizens. They should be helped and allowed to live in the community unless there is definitive proof that an alternate setting is more appropriate or beneficial.

We must judge each person according to his own abilities. We must abolish the double track system that applies one legal standard to the mentally retarded and another standard to other people.

By making it possible for mentally retarded individuals to enjoy the rights they are entitled to as Americans, we fuse the silent minority with the free majority. We reaffirm our forefathers' belief that all men have unalienable rights to life, liberty and the pursuit of happiness.

"Justice is not only legal protection and social order. Justice is not simply external relations and behavior. It is also an ordering of the various values, attitudes and tendencies within the inner person.

"What does it mean to us and what does it do to us as persons to violate other people's rights as we have done? More importantly, what does it do to us to shut other people out of our world, to create a world in which our moral community does not include whole categories of people?

"Do we become diminished as people if we participate in the myths and stereotypes that have led to this kind of unequal treatment? Are we becoming a less nurtured people? How important is nurturance for our biological evolution?

"We want to help the mentally retarded. We also need to focus on ourselves, our attitudes —on what we have to learn from the mentally retarded, not simply what we have to give them.

"So when we raise a question about humanizing, I ask, 'Who is it that really needs the humanizing? Is it the mentally retarded person, or is it us!'"

Professor Karen Lebacqz
Pacific School of Religion

Further information on legal rights of mentally retarded citizens can be obtained through most of these organizations. Others provide beneficial background literature and opportunities for you to become an involved citizen for the rights of the silent minority.

Accreditation Council for Facilities for the Mentally Retarded, Suite 2201, 875 North Michigan Ave., Chicago, Ill. 60611

American Association on Mental Deficiency, 5201 Connecticut Ave., N.W., Washington, D.C. 20015

American Orthopsychiatric Association, 1790 Broadway, New York, N.Y. 10019

American Psychological Association, 1200 — 17th Street, N.W., Washington, D.C. 20036

Center for Law and Social Policy, Mental Health Law Project, 1751 N Street, N.W., Washington, D.C. 20036

Council for Exceptional Children, 1920 Association Drive, Reston, Va. 22091

Health Insurance Association of America, Information and Research Division, 750 Third Ave., New York, N.Y. 10017

National Association for Mental Health, 1800 N. Kent St., Arlington, Va. 22209

National Association for Retarded Citizens, 2709 Avenue E East, Arlington, Tex. 76011

National Center on Law and the Handicapped, 1235 N. Eddy Street, South Bend, Indiana 46617

President's Committee on Mental Retardation, Regional Office Bldg. #3, 7th and D Streets, S.W., Washington, D.C. 20201

Senate Subcommittee on the Handicapped, Committee on Labor and Public Welfare, New Senate Office Bldg., Rm. 4232, Washington, D.C. 20510

State Bar of Wisconsin, 402 W. Wilson Street, Madison, Wisc. 53703

United Cerebral Palsy Association, Inc., 66 E. 34th Street, New York, N.Y. 10016

U.S. Department of Health, Education, and Welfare, Office of Child Development, Education for Parenthood, P.O. Box 1182, Washington, D.C. 20013

U.S. Department of Health, Education, and Welfare, Office of Mental Retardation Coordination, Washington, D.C. 20201

WHAT YOU CAN DO

To give the retarded "silent minority"
The rights to life, liberty and the pursuit of happiness

If you are a layman . . . .

Be a citizen advocate for a retarded person. Apply to your local Association for Retarded Citizens.

Support local measures that enable the retarded to enjoy full rights.

If you are an attorney . . . .

Familiarize yourself with the special legal problems of retarded citizens.

Encourage consideration of these matters in law schools and bar associations.

If you are a public official . . . .

Review the effect of your programs on the retarded.

Take any steps necessary to make them fully responsive to the rights of retarded citizens. Improved programs can prevent lawsuits.

Credits

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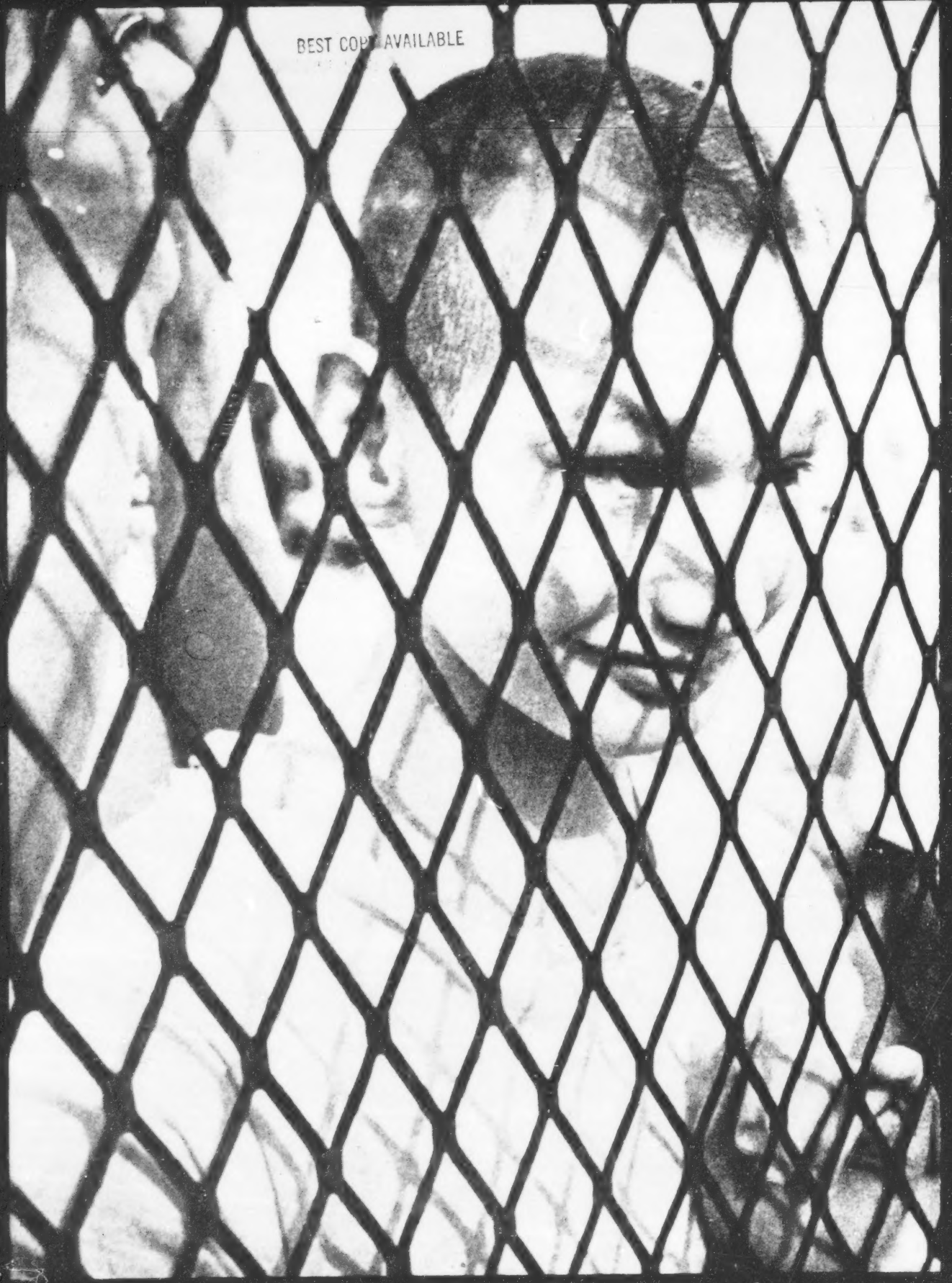

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THE WHITE HOUSE

WASHINGTON

April 11, 1973

As a lawyer, I am keenly aware that until recently lamentably little attention has been given to the legal rights of our retarded citizens. This Conference on the Mentally Retarded Citizen and the Law gives national focus to this important priority, and I warmly commend all those who will be taking part in its sessions.

While the law must treat all citizens impartially, that objective cannot be achieved without taking into account the special problems of the retarded. Since these problems affect some ten percent of our population when the families of the retarded are included, they deserve the most serious consideration of those who are concerned with bringing about true justice under law.

By giving millions of retarded Americans ready access to the legal system, we guarantee their inalienable rights as citizens and strengthen the fiber of our society. I look forward to the results of these constructive deliberations, and hope that they will serve to advance this worthwhile effort.

Richard Nixon